

TO GET X HER[®]
TURNER SYNDROME FOUNDATION

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LETTER FROM THE PRESIDENT

It's been eleven years since my daughter's diagnosis with Turner Syndrome. There are so many people who helped **to get her** through the journey that begins with a diagnosis. It amazes me how little people know about Turner Syndrome. Like many parents who reach out daily for support, we were completely overwhelmed.



We embraced the diagnosis rather than concealed it. Social change is possible when people lean **together** to solve problems. There is power in belonging and having purpose. People of all backgrounds and abilities are getting involved.

A diagnosis changed our lives. This mission saved it.

In the following pages, read more about the Turner Syndrome Council on Cardiology, a current initiative transforming cardiac care for TS patients to save precious lives. Read about our invaluable volunteers, their efforts, and how these experiences are impacting lives. *Purpose.*

This year's theme, 'ToGetHer,' embodies a spirit of action to propel this cause and to help the people we love. **To get her** help proved fortuitous for my child. She went from being perceived as 'rare and sick' to belonging to a group of 1 in 2,000 exceptional survivors. *Hope.*

I am grateful for all of the supporters and the personal growth derived from this unexpected journey. A gift of your time or financial support helps us reach for the stars of possibilities. *Support.*

Thank you for coming along on this journey. We are so happy you are here.

Sincerely,

Laura Fasciano
Founding President & Executive Director



TURNER SYNDROME FOUNDATION

Turner Syndrome Foundation (TSF) was formed in 2008 when one mother, faced with a diagnosis for her young daughter, found the Turner Syndrome narrative to be littered with disparaging information and minimal support. Established as a 501(c)3 nonprofit organization just one year later, the Turner Syndrome Foundation has experienced great growth and recognition and remains a beacon of hope for everyone affected.

Turner Syndrome Foundation provides life-saving resources to the Turner Syndrome community. Turner Syndrome (TS) is a genetic condition that affects 1 in 2,000 females and occurs when one X chromosome is completely or partially missing. TS is completely random, meaning any girl or woman could be affected – your daughter, your sister, your aunt, your friend. Between 97-99% of Turner Syndrome pregnancies will result in miscarriage. Those who do survive will require a lifetime of medical care for a number of issues, commonly short stature, delayed puberty, heart abnormalities, diabetes, and hearing loss.

The goal of the Turner Syndrome Foundation is to support research initiatives and facilitate education programs that increase awareness and enhance medical care of those affected by Turner syndrome. Early diagnosis and comprehensive treatments over the lifespan are promising for a brighter and healthier future for all young girls and women with Turner Syndrome. Turner Syndrome Foundation collaborates with patients, physicians, educators, legislators, and researchers to fulfill our mission through our four program areas of awareness, advocacy, education, and research. TSF serves more than 20,000 individuals through our patient and professional education workshops, national awareness athletic events, research registry, and open-access education resources.

Since 2009, Turner Syndrome Foundation has seen tremendous successes as a result of our programs. TSF introduced a Patient Registry to better understand the patient population and their needs. In 2018, we are happy to report that this registry has expanded to include the Turner Syndrome Research eXchange (TSRX), a patient-centered registry focused on influencing TS research and advocacy. In addition, TSF has partners with countless medical centers and universities to increase TS education. Our vision of hope and possibility for the future of Turner Syndrome care permeates every program as we continue to improve and expand.

TSF is unique because programs are offered without charging dues. We believe all information should be open-access in order to reach the greatest number of patients. In addition, our resources are a collaborative effort, with contributions from the people who know TS best: professionals and TS girls, women, and caregivers.

IMPACT

WHO WE SERVE



3,043 Women & Girls



8,112 Family Members



5,929 Medical Professionals



10,000 Volunteer Hours

67,000+

Annual Website
Visitors

600+

Awareness Month
Petition Signatures

7,000+

Team TSF
Participants

100+

TSRX
Members

2,500+

Education Program
Learners



Cost to Access TSF
Support & Resources

SIGNATURE PROGRAMS

Personalized Care & Support

Turner Syndrome Foundation freely provides support and resources as a measure of care to patients and caregivers.

“Every call, every email, every personal visit is attended to as though it is coming from a family member.”



Team TSF Events

Through our partnership with national events, everyone everywhere can participate and fundraise in organized athletic events.

“We were excited to meet other families and, for the first time, be given valid information about TS! We no longer felt that we were the ‘only’ family going through this.”

Turner Syndrome Retreats

An educational program designed to increase feelings of self-worth by providing a space in which new relationships can develop and thrive.

“Words can’t adequately describe what an honor it was having the opportunity to be a part of such an amazing weekend.”





February & Everyday Awareness

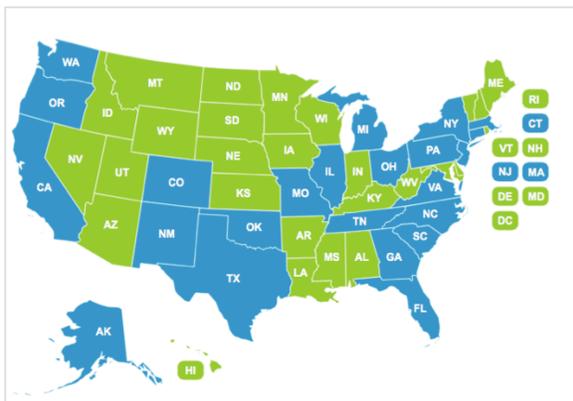
A toolkit and peer support provides resources to advocates everywhere, working as one community to raise awareness.

"Turner Syndrome Foundation [is] an amazing organization...bringing awareness to pediatricians and other pediatric specialists, medical students and legislators."

Patient Education

Connecting medical education and the patient community through workshops and online resources to foster healthier futures.

"I reached out to the TSF because I felt lost and alone. They have been a blessing to us! We learned so much about TS."



Access to Care

Mapping a network of specialized Turner Syndrome care, making it easy to find at www.TurnerSyndromeFoundation.org.

"We are now supported by a great community...from friends, family, teachers, to doctors!"

RESEARCH

Turner Syndrome affects 1 in 2,000 females randomly. Currently, there is nothing you can do to prevent it and science is unsure what causes it. TSF recognizes that research is the key to understanding the mysteries of this condition. The TSF Research Committee meets quarterly to stay up-to-date with emerging studies and opportunities.



Introducing Juliann Savatt

TSF welcomes Juliann Savatt to the TSF Research Committee as Registry Advisor. Juliann received her Master of Science in Genetic Counseling from UNC Greenboro. She is a board certified and licensed genetic counselor who currently sees patients in the Geisinger Autism and Developmental Medicine Institute in Lewisburg, Pennsylvania. In addition to her clinical role, she is motivated to empower patients to be active partners in genomic discovery and is working towards that goal by coordinating GenomeConnect, the ClinGen patient registry.

Turner Syndrome Research eXchange

TSF understands that patients hold the key to advancing science and medicine. As a result, TSF in collaboration with Invitae Patient Information Network initiated the Turner Syndrome Research eXchange (TSRX), a registry that invites patients to unlock data for a greater transparency of Turner Syndrome. www.TSRX.us



Patient-Centered Research

TSF partners with leading universities, research centers, and more to encourage patients to participate in important studies. TSF is named in ongoing research studies at Emory University, Rutgers College of Public Health, and Stanford University Center for Brain Sciences Research. Studies include:

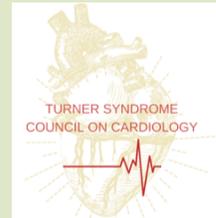
- Coriell Laboratories Human Genetic Cell Repository*
- Transitional Care Task Force*
- Neuropsychological Testing*
- UT Health Congenital Heart Defects*

PROFESSIONAL EDUCATION

TSF educates physicians and educators through CME activities, committees, and more to increase understanding and lower diagnosis age. The TSF Education Committee meets quarterly and is dedicated to promoting academic success for TS students.

Council On Cardiology

Every day, lives are lost to the cardiovascular issues of Turner Syndrome. TSF has organized the Turner Syndrome Council on Cardiology (COC) of industry leading professionals to address these complex cardiovascular issues. The COC seeks to tackle the gaps in diagnostics, treatments, transition, emergency episodes, and preventative cardiac care.



COC Members:



Sheetal Patel, MBBS, MD, MSCI, COC Chairperson

Dr. Patel is a pediatric cardiologist at Ann & Robert H. Lurie Children's Hospital of Chicago, where she is a member of a Turner Syndrome multidisciplinary team. She is passionate about prenatal diagnosis of congenital heart defects, with a special interest in providing cardiac care to patients with Turner Syndrome.

Helen Binns, MD, MPH

Hina W. Chaudry, MD

Jaharm Chelluri, MD

Allan J. Fischer, MD

Pankaj Madan, MD

Michael C. Monge, MD

Khoa N. Nguyen, MD

Andrada R. Popescu

Marlon S. Rosenbaum, MD

Karen Rubin, MD

Luciana T. Young, MD



Darlene Foschini-Field, PhD, TSF Medical Director

Dr. Foschini-Field has over 20 years experience in medical education, including women's health and pain management. Since joining TSF as Medical Director, Dr. Foschini-Field has been influential to the development of the COC.

Educating The Educators

TSF in partnership with Kean University hosted the first ever "Educating the Educator's" conference for teachers, school nurses, social workers, and administrators. The event offered continuing education credits to attendees to help better serve their students. The TSF website also features open-access resources for educators, including a professional registry, to foster an optimal learning environment.





WHY TAYLOR VOLUNTEERS

"I found out about Turner Syndrome through a genetics class. Upon researching TS, I found that knowledge about this disorder is severely lacking, and wanted to help spread awareness and a sense of community. I found the Turner Syndrome Foundation and was amazed that an organization dedicated to awareness, support, and research. Every week I see the time, love, and work that Laura and the volunteers here put into helping individuals with Turner Syndrome. I'm very lucky to be involved in such a place and see the work that they do."

WHY RACHEL RUNS

"Recently, I decided that I wanted to take on the daring and arduous challenge of running a marathon on all 7 continents while raising money for the Turner Syndrome Foundation. TSF has the capability to build strong, genuine friendships between women, regardless of background. It does not matter how experienced of an athlete you are, or whether you have or know someone with Turner Syndrome. There is room for everyone in this organization."



WHY DANA ADVOCATES

"This is the 6th year I have proclaimed February as Turner Syndrome Awareness Month in Pennsylvania! I was determined to get someone to hear our story. A gentleman on the Senate floor lost his baby girl in utero to Turner Syndrome. He shared how scared he and his wife were, that doctors and medical professionals had little to no knowledge of Turner Syndrome, and when they searched the Internet they became overwhelmed. I needed to fight for her and ALL the families who our on this journey, because we are in this together. NO ONE should be alone or scared."

VOLUNTEERS IN ACTION

TSF has nearly 300 volunteers representing 33 states! Email volunteer@tsfusa.org to find a volunteer opportunity that's right for you!

LOOKING FORWARD

In 2018, Turner Syndrome Foundation initiated a number of projects that have been in development for some time, like the Autumn Retreat and Council on Cardiology. These initiatives represent TSF's program areas of awareness, advocacy, education, and research to further our mission. Over the past nine years, TSF has expanded and evolved to meet the needs of the Turner Syndrome population, from expectant parents to adult women. But our work is far from done.

Our vision for 2019 and beyond is to grow our network of support to include leaders from industries that have the power to change the future of Turner Syndrome care – from medical professionals to legislators, from educators to researchers. Our goal is to provide every expectant parent with hopeful support, to afford every TS girl the opportunity to receive proper care made possible by an early diagnosis, and to ensure care transcends throughout the lifespan.

You have a hand in changing health outcomes throughout all life stages. With your investment we look forward to making this vision a reality together.



FINANCIALS

Turner Syndrome Foundation is proud of our generous donors who enable us to continue serving the Turner Syndrome community. As we look forward toward growing our network of support, we remain committed to our donors.

TSF FINANCIAL SNAPSHOT

Volunteers are our greatest asset, generously offering their time and expertise to this mission. The value of our volunteers totals **\$150,000**.

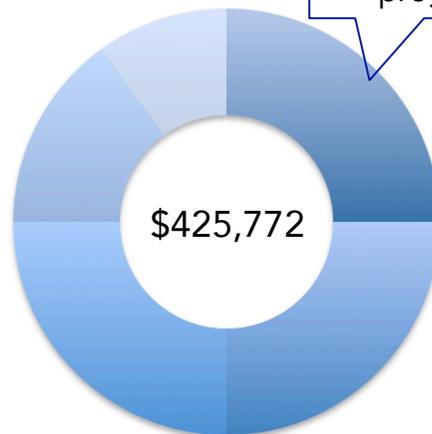
90% of expenses go directly to programs.



INCOME

General Contributions	39%
Grants	34%
Special Events	13%
Peer-to-Peer Fundraising	11%
Other	3%

This information is available on GuideStar.



EXPENSES

Programs	
Awareness	25%
Advocacy	25%
Education	25%
Research	15%
Administration	10%

CORPORATE SUPPORTERS



WORKING TOGETHER

Together, we can do so much more. Every step we take to educate professionals, support patients, and raise a greater awareness, we take with you by our side.

GIVE. Monthly donors sustain our mission throughout the year. Multiply your impact while still keeping your budget in mind by spreading your donation over a year.

Become a \$1,000 major donor by giving just \$83 a month!

\$100 – You can help provide care and support to a newly diagnosed patient.

\$250 – You can help girls receive an early diagnosis to improve care outcomes.

\$500 – You can help foster a greater understanding of TS.

\$1,000 – You can help cultivate a culture of advocacy.

\$5,000 – You can help save lives through research opportunities.

VOLUNTEER and join the life force of our mission, while being a role model and inspiring others. Host an event, become a local leader, and more. We always welcome new volunteers. Email volunteer@tsfusa.org to get started.

PARTNER with us. Join our team of corporate partners to make a major impact. Opportunities include leadership positions, event or program sponsorships, and more!

LIKE us on Facebook @TurnerSyndromeFoundation and follow us on Twitter @TeamTSF to stay up to date on the latest TSF news!

WHY VALLYE GIVES

"The day of our final sonogram, we both knew in an instant that our lives were changed forever. No heartbeat was detected. As a parent, you just never expect to attend the funeral of one of your children. So we choose to give each year at this time in honor of our sweet child Hannah and in honor of all of those lives who are touched by Turner Syndrome. While there may be tears in our eyes because of our loss, education and research can help those affected live better."



Board Members

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Olivia Gonzalez
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